

## ONTARIO'S HEALTH-INFORMATION SERVICE A PROVINCE-WIDE RESOURCE FOR PATIENTS

**Halyna Koba**

### In Brief • En bref

An innovative service based in Toronto provides consumers with specialized yet understandable information about health care and health promotion. The Consumer Health Information Service gathers articles from medical journals, periodicals, health agencies, support groups, books and medical databases to provide people with better access to readily understandable health information. Much health-related information is available, says the chief librarian, but often people have trouble determining where it is.

Un service novateur de Toronto fournit aux consommateurs des renseignements spécialisés mais compréhensibles sur les soins de santé et la promotion de la santé. Le Consumer Health Information Service réunit des articles de journaux médicaux, de périodiques, d'organismes du secteur de la santé, de groupes d'appui, d'ouvrages et de bases de données médicales afin de fournir aux gens un meilleur accès à des renseignements faciles à comprendre sur la santé. Il y a énormément de renseignements sur la santé de disponibles, déclare le bibliothécaire en chef, et l'on a souvent de la difficulté à les trouver.

**B**ased on the premise that health is a personal responsibility, an innovative information service located on the second floor of the Metropolitan Toronto Reference Library is providing consumers with specialized and understandable information about health and health promotion.

The Consumer Health Information Service (CHIS) is a joint project of the Faculty of Library and Information Science and the Centre for Health Promotion at the University of Toronto, the Ontario division of the Consumers' Association of

Canada (CAC), the Metropolitan Toronto Reference Library and the Toronto Hospital. It opened in February 1992 and currently is staffed by two full-time librarians and four part-time employees, including a library technician from the Toronto Hospital. "The concept is that patients are responsible for their own health," said senior librarian Susan Murray. "There is real empowerment when they take control and understand what's happening."

Studies have shown that people involved in their own care are more comfortable about treatment options, have a better state of mind when

they sense they're making the decisions and have more favourable health outcomes, she added.

The idea for the service was developed by Rose Rubion, past chair of the health committee of the Ontario branch of the CAC. The CAC argues that consumers have the right to be informed and to participate in decision making affecting their health. "Access to health information can help make these goals a reality," states a CHIS fact sheet.

However, as Murray pointed out, "there may be a lot of health information but many times people have trouble finding out what and where it is."

Accordingly, the emphasis at CHIS is on easy accessibility. Toronto residents can visit personally or telephone a reference service (416 393-7056) while other Ontarians can call toll-free (800 667-1999). A thorough consultation with clients ensures that CHIS staff provide the most useful information, but no medical advice or interpretation is given, nor are any decisions made for callers. "If someone asks about care and treatment, we provide the range of information," said Murray, but staff make it clear that the information is not a substitute for consultation with a health care professional.

The collection features about

*Halyna Koba is a freelance writer living in Toronto.*

350 subject files — ranging from Abnormalities to Women's Health, based on National Library of Medicine headings and Library of Congress categories. Information is also available on different types of complementary medicine such as acupuncture and herbal treatments. Material includes clippings from 150 current periodicals, a list of associations and support groups, and other pertinent information including brochures.

Staff make an effort to collect health care publications not widely circulated outside the medical profession, such as newsletters published by the Multiple Sclerosis Society of Canada and the Brain Tumour Foundation of Canada and medical magazines and journals.

CD-ROM databases are also used to provide the latest health news. The general Health Reference Centre, the main database, contains either full texts or synopses of articles from more than 160 health and medical journals and 300 general-interest journals, dating back more than 4 years. There are also 500 medical-education pamphlets and 5 leading medical reference books. A specialized database, Patient Drug Information, contains information on 7700 prescription and nonprescription drugs. Information is available on chemicals and occupational health and safety issues, and CHIS staff can access other databases such as *Medline*. Other resources include about 1500 consumer health books, guides and reviews.

Customized information packages are prepared on request and may offer photocopied articles, the names of related organizations and book lists. Services, both personal and telephone, are confidential and free. CHIS staff also refer information seekers to other agencies.

Most of the financing is provided by government. The Health Strategies Fund of the Premier's Council on Health, Well-being and Social Jus-

tice provided \$417 000 for the pilot stage and the Ontario Ministry of Culture, Tourism and Recreation contributed \$20 000. The 1994–95 operating budget is covered by a \$244 000 grant from the Health Promotion Branch of the Ontario Ministry of Health, plus donations. Support services such as public relations and cataloguing are provided by the Metropolitan Toronto Reference Library.

Peter Coleridge, acting director of the Health Promotion Branch, said the ministry is interested in "the whole area of consumer health . . . in terms of increasing access to information around various health issues — alternate therapies, for example, for treating colds, and information on indirect factors which [affect] people's health — the environment, for example."

Joanne Marshall, associate professor in the Faculty of Information Studies at the University of Toronto, wrote the proposal for the original funding and was chair of the Management Committee for 18 months. She now sits on the Advisory Committee. "It's quite remarkable that CHIS has the continuing strong support that it has," she said. "It really shows the strength of the idea."

Who uses the service? To date, the youngest client was a 7-year-old girl, calling from school, who wanted to know about nutrition. The oldest was a 94-year-old woman interested in preventive medicine. Typical callers have included a consumer asking about cataract surgery and possible adverse effects and a woman in her 50s who wanted to know more about hormone-replacement therapy. Some of the calls have been from professionals. In one case, a pharmacist requested information for a customer about a certain drug. Some public-health professionals, often in remote areas, also call, seeking patient material on a variety of health care issues.

An early client profile indicated

that about 75% of users were female; about 68% were lay people, with the remaining 32% including health care professionals, journalists, librarians, students and teachers. About 66% wanted information about a disease or injury; other requests concerned health promotion (6%), CHIS itself (6%), drugs (6%), surgery (5%), therapies (3%), health determinants (3%) and the health care system (2%).

Reasons cited for using CHIS included:

- The perception that physicians tend to be more receptive to patient inquiries if patients have a basic knowledge of health problems;
- A communication gap between the physician and patient because of technical medical terminology or the doctor's busy schedule;
- Consumer frustration with the health care system;
- The informed consumer's ability to give health care providers better information that results in a specific diagnosis and earlier treatment, etc.; and
- Consumers' desire to make well-informed decisions that make them feel they are in control of their own bodies and health.

Murray says the demand for CHIS services is growing, even among health care professionals and librarians. Questions are getting more specific and technical, and there are a substantial number of repeat clients. "In a sense, we act as travel guides. . . . Over time, the staff builds up an ability to make connections, and find sources of further information."

One telephone call on the toll-free line came from a woman who wanted to know why she was always so tired and needed to rest. She wondered if she had chronic fatigue syndrome. At the end of the call, when Murray asked her age, the caller responded: "89 years." ■